

BREAKING GROUND



MEET THE 2006 YOUTH LEADERSHIP FORUM STUDENT DELEGATES [12]

INSIDE:



THE COUNCIL SALUTES
THE 2005-06
GRADUATING PARTNERS
CLASS
[4]



KOSOVO: A COUNTRY
WHERE EVERYONE IS
WAITING
[6]



MARTIN MCGRATH:
LEADING BY EXAMPLE
[16]



CONTENTS

- 3** Two Impressions of Access to Art Through Touch
- 4** The Council Salutes the 2005-06 Graduating Partners Class
- 6** Kosovo: A Country Where Everyone Is Waiting
- 7** Book Review: *Able!*
- 8** Scott Wyatt Promotes the Importance of Work in New Creating Jobs Initiative
- 10** News From Pathfinder
- 11** Tennessee Spotlight
- 12** Meet the 2006 Youth Leadership Forum Student Delegates
- 14** Arlington Developmental Center: The Closing is in Sight
- 15** Annual Arts Issue
- 16** Martin McGrath: Leading by Example
- 17** Bill to Create Task Force to Plan for Developmental Disabilities Services Passes State Legislature
- 18** Promoting a Balanced Long-Term Care System in Tennessee

Cover photos: Youth Leadership Forum 2006 Delegates

CONTACT INFORMATION



This free publication is produced six times a year by the Vanderbilt Kennedy Center for Research on Human Development and Kent Communications Group. Subscription requests, change of address, and submissions for possible publication should be directed to: Breaking Ground, Council on Developmental Disabilities, 500 Deaderick Street, 13th Floor Suite 1310, Nashville, TN 37243. **PHONE:** 615-532-6615. **E-MAIL:** breakingground@vanderbilt.edu.

Tennessee Council on Developmental Disabilities Grant Number 1-03999-1-0. Authorization Number 339371, July 2001. 5,600 copies. This public document was promulgated at a cost of \$.46 per copy.

TWO IMPRESSIONS OF ACCESS TO ART THROUGH TOUCH

By Carol Francisco and Sally Ann Gentry

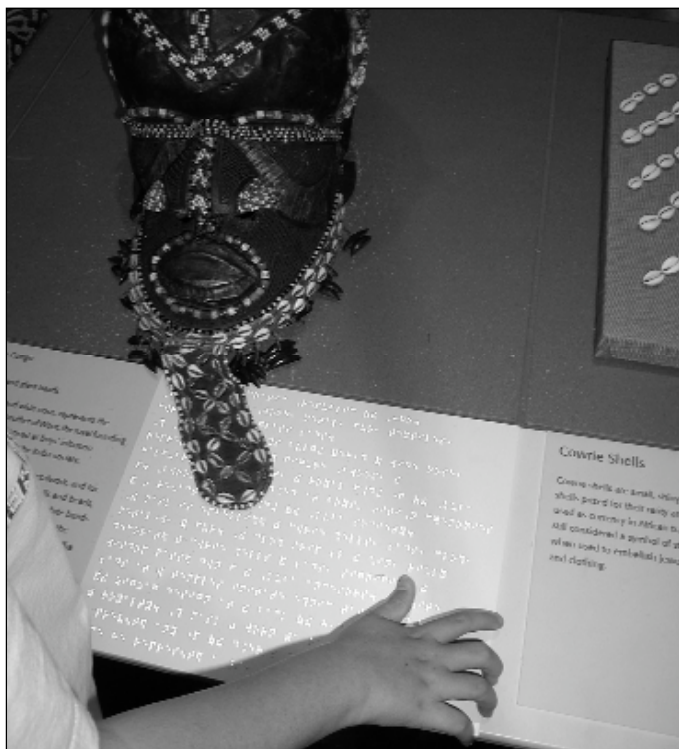


PHOTO CREDIT: FRIST CENTER FOR THE VISUAL ARTS

Art has never been something I thought much about. After all, I have been blind since birth. I have no concept of colors, perspective, depth perception and many other things. Information about the world around me is obtained through sound, touch and the descriptions given by others. All small children grow up hearing the words "don't touch," but while the reasons for this are often obvious, at times I felt isolated and not completely aware of my environment.

Certainly museums must protect valuable and fragile items from damage that could be caused if they are handled. This makes providing meaningful access for people with visual impairments very challenging, and, until the last 20 years or so, very few made any attempt to do it. For those who developed visual impairments as adults, their memories of visual images can help them to create a mental image when paintings or photos are described clearly and in detail.

However, for someone like me, with no mental picture of the sky at night or the view from the top of a mountain, descriptions are of very little benefit. It is similar to describing the difference in sound between a violin and a trumpet to someone who never heard music. Therefore, my only real access to art can be through the sense of touch.

The Frist Center for the Visual Arts' first attempt to make art accessible through touch was its recent African Arts exhibit [Beyond Sight: African Art Touch Gallery; January 27-April 30, 2006]. I visited the exhibit with a friend, who lost her sight as an adult, and with her husband, who has normal vision and whose descriptions were very helpful. The building itself is very accessible, with accessible parking, doors that automatically open and wide aisles.

The sculptures and masks we touched were made of wood and were decorated with beads or cloth and were carved in great detail. Each had a description beside it that was written in Braille and large print. There was a doll, which was supposed to represent fertility. A mythical animal had two large horns that felt like straw or corn stalks. There was a dog with many nails stuck in it. Each nail was placed by a medicine man or healer and represented an illness or problem that a member of the community needed to get rid of.

My favorite was the figure of the medicine man or healer who had a mirror in his belly. The mirror protected the herbs, fur and plant material used for the medicines. These figures were used in ceremonies or kept at home and were common in the 1800's and early 1900's. There were also several ceremonial masks, many with elaborate headdresses. One felt like a helmet. I could feel the facial expressions on these wooden masks, which were used for dances and ceremonies. Some were quite fierce and others were happy. We also felt examples of different types of beads and shells.

The Braille descriptions were helpful, although I found some errors and missing dots that had to be corrected. Some of the figures were quite tall and set back on the table, and anyone using a wheelchair or even a short child would have had trouble reaching them. In spite of these minor difficulties, this was a good first effort. I do think more could have been done by making ceramic models of the statues in the rest of the exhibit and replicas of the jewelry using cheap metal and beads. I saw this done in Memphis years ago at an Egyptian exhibit.

The museum also provided descriptions of the artwork on tape. These were very good, describing the items in the pictures and photographs and explaining what the artists meant to convey. However, many of these descriptions were given by the African artists and collectors themselves and at times they were difficult to understand. These descriptions gave a great deal of information about the history, customs and cultures of several rural African tribes. Just as in our own Native American cultures, many of these traditions have vanished or nearly disappeared.

CONTINUED ON PAGE 11

THE COUNCIL SALUTES THE 2005-06 GRADUATING PARTNERS CLASS

By Ned Andrew Solomon



PHOTO BY PEGGY COOPER

Since 1993, the Council has been hosting the Partners in Policymaking™ Leadership Institute, designed to provide adults with disabilities and family members with advocacy and self-advocacy training, and information on a wide range of disability topics. Over the course of seven week-ends, Partners participants learned about employment and home ownership opportunities for persons with disabilities, promoting inclusive education and building inclusive communities, working with the media and legislators, assistive technology options, Tennessee's disability services and resources, and landmark disability legislation.

They also had the opportunity to learn about the challenges and successes of other adults with disabilities and family members, while sharing their own.

On April 22nd, the 2005-06 Partners class graduated in a ceremony at the Nashville Airport

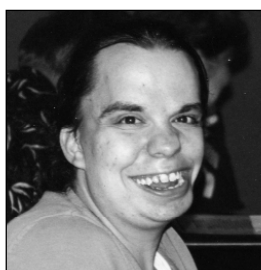
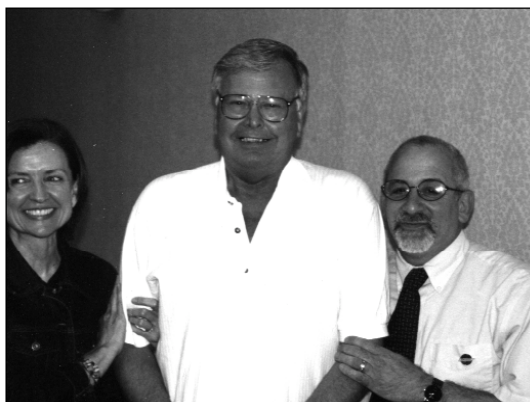
Marriott. The expectation is that these trained individuals will reach out into their communities to help others create better informed and more integrated lives.

Please join us in congratulating the following persons from across the State for completing this year's Partners training:

MERRY ADAMS, SMYRNA
 MELISSA ALLEN, MEMPHIS
 ADAM BALLARD, LAKE LAND
 BRUCE BENTLEY, NASHVILLE
 ANGELA BRAACH, MURFREESBORO
 DEBORAH BUTLER, KNOXVILLE
 SUZETTE BYRD, MARYVILLE
 JENNY CATES, COLUMBIA
 KIRK DAVIS, NASHVILLE
 GWEN DYER, MURFREESBORO
 CAROL FRANCISCO, NASHVILLE
 STACE HARRIS, CORDOVA
 PAM HEROLD, HENDERSONVILLE

ROBIN LINER, HARRISON
 KAREN MEVIS, KINGSTON SPRINGS
 JOHN PIVER, JOHNSON CITY
 RICKY POWELL, NASHVILLE
 ANITA ROBINSON, MEMPHIS
 LAUREL RYAN, COLLIERVILLE
 AMY WALLACE, NASHVILLE
 SUZETTE WEBSTER, NASHVILLE
 PERRY WEEMS, GREENEVILLE
 WILLIE WELLS, CORDOVA
 SHARA WINTON, MURFREESBORO

Lori Siegal, of Memphis, passed away before the third Partners session of the 05-06 season. The tremendous impact Lori had on her classmates in a very short time—and her invaluable contribution to her community as a self-advocate and advocate—convinced the Council that Lori should be our first "honorary" Partners graduate.



FOR MORE INFORMATION ABOUT
THE PARTNERS IN POLICYMAKING™
LEADERSHIP INSTITUTE,
PLEASE CONTACT PARTNERS
DIRECTOR, NED ANDREW SOLOMON
AT 615-532-6006,
OR BY E MAIL AT
NED.SOLOMON@STATE.TN.US.

KOSOVO: A COUNTRY WHERE EVERYONE IS WAITING

By Ruthie-Marie Beckwith, Ph.D. and Mark Friedman, Ph.D.

Stepping onto the tarmac in a former Communist country was a very solemn experience for these two American consultants, who, while well traveled, spend most of their time on Tennessee's back roads and highways. However, there we were, disembarking our Austrian Airlines plane at Pristina, the capital of Kosovo, a country now under the protection of the United Nations.

After navigating a long line of other "consultant looking" passengers being processed through customs and having our passports inspected and stamped, we were met by Dea Pallaska, the director of Mental Disability Rights International's Initiative on Inclusion.

As we rode in a cab to the hotel—we learned later that few actually owned cars—we were greeted at the edge of the city by a huge billboard depicting former President Clinton, considered by most Albanian Kosovars to be the savior of Kosovo. Dea reviewed our schedule with us as we unloaded our bags and made plans to meet for dinner. Thus began our indoctrination and sobering eight days of work within a country that is not quite a country, with individuals who, until very recently, were treated as not quite citizens. We hope that some excerpts from our travel notes will provide insight into the dynamic and long road to a civil society these individuals with disabilities and their families are traveling.

• **NOTE 1** | Hannah arrived along with 35 of her colleagues from three distant villages. Their self-advocacy groups had been meeting once a week for the past six months. Some had gone to drink coffee at a local Kafe shop for the first time. Others had recently voted for the first time in their country's first free election. An avalanche had blocked the road to Hannah's village and she had been unable to get five euros

to take the train. Still determined to come to the training, she walked alone for two hours on the train track to get to the point where she could catch the bus.

• **NOTE 2** | We shook hands with each and every one of the 200 people languishing at Shtimë. Ten "day rooms" held 20 people each with only two staff people present. Everyone was huddled together—the rooms were cold, the floors bare, and the walls barren with paint peeling—onto sofas, talking softly and smoking cigarettes. No one had their own clothes or personal possessions. One young woman asked us to help her find her family. No one knew whether they had survived the war.

• **NOTE 3** | Tonight we heard the story of Halit Ferizi, the founder of Handikos who incurred a spinal cord injury in the early 90's. After being airlifted to a rehab facility by the Czechoslovakian army, he decided to return home and find out if there were others out there like himself. Ten years of hard work made it possible for Handikos to be there for people with disabilities who had made their way to the refugee camps.

• **NOTE 4** | The only instructor teaching coursework about individuals with disabilities at the local University is a biology professor. In the medical program, four physical therapists have graduated and are now available to serve the entire country. Sixty people crowded into our training on how to teach people with cognitive disabilities. Our sample communication boards—hastily created with local construction and contact paper—were passed reverently around the room. Until then, no one had thought that people with cognitive disabilities could learn to communicate. After the training, one of the Handikos volunteers came forward to share her photo album of training they are providing on safe feeding practices.



LEFT: DEA PALLASKA

BACKGROUND: KOSOVO

Kosovo currently has a post-war society. Bombing by NATO in the late 90's occurred at the behest of the United States in an effort to stop Slobodan Milosavic's campaign of ethnic cleansing. Nearly 200,000 individuals fled to refugee camps in neighboring countries. At a minimum, an estimated 50,000 individuals in Kosovo have a mental disability (cognitive and mental health). Of these, only 250 people in the entire country of Kosovo receive government services. Two hundred of these are institutionalized at Shtimë and another 50 have found their way into predominately foreign supported segregated community services. A pension of 40 euros per month (approximately 60 U.S. dollars) is allotted to individuals with disability. With unemployment running at a rate of 70%, the individual's entire family typically relies on this pension as their sole source of support. Handikos, a non-governmental organization, has been, until recently, the only organization offering support of any kind primarily to individuals with physical disabilities. Without the efforts of initiatives such as the one by MDRI, individuals with mental disabilities would surely continue to be not seen and not heard.

CONTINUED ON PAGE 9

ABLE, INDEED! BY NANCY HENDERSON WURST

Book review by Amy Petula

What happens when you combine a father with a work ethic of the 50's, a son with the idealism and desire for positive change of the 60's, two very different groups who had endured varying degrees of prejudice through the 70's, put them all together in the 80's in a small southern company making indoor outdoor carpet, and add healthy doses of vision, nontraditional thinking, and a willingness to send packing both bigots and "the system," with all its rules, paperwork, and holding people back? SUCCESS, in capital letters, through the 90's and right into the 21st century. In short, Habitat International. The story of this remarkable company is detailed in the book *Able!*, by Nancy Henderson Wurst.

Able! tells how David Morris, the artistic, forward-thinking son of northwest Georgia entrepreneur Saul Morris, rocked the establishment with an experiment that changed the world of the Morrises, as well as a number of people with "distractions," as their differences are called at Habitat International. Before being approached with this experiment in 1986, Habitat already had a number of Cambodian workers who had spent years as slave laborers in a Khmer Rouge prison camp, before eventually making their way to America and the Habitat "family." Even so, David Morris had his reservations when asked about hiring an enclave of workers with physical and mental disabilities. However, what began as a two week test has blossomed into a success tale that other businesses would do well to emulate, a tale Mr. Morris and Ms. Wurst are sharing with individuals and workplaces throughout the country. Mr. Morris quickly discovered that, with a little extra training on the front end, not only was his new workforce "able," they were more than willing, had a very low rate of turnover and absenteeism, zero accidents, zero back-orders, and fewer, not more, supervisors.

In fact, the company did so well, it outgrew its Northwest Georgia plant. Habitat tripled its sales, and, in October 2003, it moved to Chattanooga. Nor did it leave its employees out of its growth. Mr. Morris rejected not only the low expectations, but also the government agencies and common practices that dictated that people with disabilities should be paid well below minimum wage. Habitat has been devoted to paying its workers, 75% of whom have a disability, a living wage, along with bonuses when the company has done well. People with all kinds of differences, from Down syndrome to cerebral palsy to autism to schizophrenia to visual impairments and more, thrived when given the opportunity to hold a "real job."

Able! chronicles the stories and triumphs of individual employees as well. From Lonny, the originator of the term "distractions" to describe the voices in his head, to Lincoln, whose bipolar disorder

didn't stop him from prodding Habitat to establish its in-house radio station, and many in between, Ms. Wurst makes clear that the accomplishments of Habitat are derived from the victories of its workers. (The radio station, incidentally, fits right in with the onsite "Happy Park," and the artwork, ranging from steel silhouettes of the employees to a mannequin with artificial grass hair to signs in psychedelic colors bearing such slogans as "Question Reality.")

Able! tells the stories of the employees, the owners, and the "Company of Positive Distractions." The lesson for business everywhere is clear—give people with differences the training and opportunity to work, and you will find them able, indeed.

Amy Petula lives in Chattanooga, is an attorney and a graduate of the 2001-02

Partners in Policymaking™ Leadership Institute.



SCOTT WYATT PROMOTES THE IMPORTANCE OF WORK IN NEW CREATING JOBS INITIATIVE

By Alicia Cone, Ph.D.

The Tennessee Department of Mental Health and Developmental Disabilities, Division of Recovery Services has launched a new employment mandate referred to as the Creating Jobs Initiative (CJI). The Creating Jobs Initiative is a strategic plan to collaborate with local Tennessee communities to increase the number of persons with mental illness employed statewide. The goal: 2,010 persons employed by the year 2010.

The CJI vision is to create and expand employment opportunities so that persons with serious mental illness and co-occurring disorders who want to work have the opportunity to choose, obtain, keep, and advance in a job. In support of that vision, the CJI mission is to assertively and strategically partner with local communities through education and information sharing.

CJI will strive to build upon collaborative, grassroots efforts and bring together stakeholders and non-traditional representatives in each of the seven statewide mental health planning regions to set goals for improving and expanding employment services. The project will also establish focused, statewide, strategic and effective community-based task forces aimed at expanding and improving employment opportunities for consumers, while simultaneously fostering and promoting full recovery and the active and meaningful participation of persons with mental illnesses and co-occurring disorders in all Tennessee communities.

As part of the CJI roll-out process, introductory sessions were held across Tennessee. I attended the session in Middle Tennessee, and heard Scott Wyatt, director of the Office of Employment, Planning and Development, introduce the initiative, which he coordinates. I was excited about the initiative, and even more struck by the passion behind Mr. Wyatt's leadership of CJI. We sat down and talked in mid-March about CJI, and Mr. Wyatt's personal perspective on the role of employment in recovery.



Photo credit: David Sherman

Mr. Wyatt painted a picture of what he sees as the effects of lack of employment opportunities for persons with mental illness and co-occurring disorders of mental illness and substance abuse; specifically, increased homelessness, incarceration and hospitalizations. Additionally, mental health consumers often try to live on \$603.00 a month, the average monthly payment from Social Security Administration Supplemental Security Income (SSI). They are frequently hesitant to venture out into the job market due to fear of losing consistent SSI and health insurance, as well as anxieties about not being able to keep a job or fit in at the workplace. It was eye-opening to realize that people with mental illness often face the same barriers as people with developmental disabilities.

According to the National Institute of Mental Health, individuals with serious mental illness are people, "over the age of 18 whose behavioral or emotional disorders meet DSM IV-R criteria and result in a functional impairment which substantially interferes with or limits

one or more major life activities." Mr. Wyatt pointed out that one of those major life activities is employment, and that the inability to work is particularly damaging for those with serious mental illness and co-occurring disorders.

Work is a part of a person's life that can affect his or her definition of him- or herself. People who work benefit not only from increased financial security but also increased self-confidence, improved opportunities for social interaction with peers, and an increased sense of hope for the future. Employment provides money, structure, a sense of purpose and identity, and facilitates a positive self-image as one contributes to the larger society.

To a significant degree, mental health consumers have been denied access to the work force, first by the challenging nature of mental illness itself and then by a mental health system and a society that stigmatizes people with serious and persistent mental illness. The reasons for the pervasiveness of unemployment among mental health consumers form a complex web of personal, traditional, financial, attitudinal, and programmatic barriers. Persons with serious mental illness and co-occurring disorders often face considerable discouragement from wary family members and mental health professionals who fear that the challenge of work will overwhelm the individual's capacity to cope.

Unfortunately, consumers often spend years trying to negotiate service delivery systems

that appear designed to maintain their status as “clients” and “patients” as opposed to allowing them the role of employee. Even when people with mental illness and co-occurring disorders make the transition into competitive employment, they frequently discover that they have no supports left to deal with inevitable employment issues, like interpersonal problems with co-workers, management of benefits, stress related to hours worked, or career goals. Therefore, the benefits of employment are sometimes lost because long-term supports necessary to maintain the employment are not in place.

The good news is that recent practices emphasize the integration of skill sets and the availability of practitioners who focus on the provision of generalized, on-going employment services and supports. These services and supports are part of a comprehensive rehabilitation process that is more person-centered and individually-directed, and includes components such as a total commitment to the person being in competitive employment, rapid job search efforts, placements based on individual preferences, indefinite follow along supports, and close and deliberate integration with the entire treatment team.

Mr. Wyatt’s background appears to be a perfect fit for his position with TDMHDD’s Division of Recovery Services. He has been a job coach and job developer, and has worked with a Social Security Administration Benefits Planning and Outreach grant project. He also has done Quality Enhancement surveys around employment for the Tennessee Division of Mental Retardation Services. Mr. Wyatt accepted the position believing it was an opportunity to build the program, grow the resources

available to people with mental illness and to make a positive change for a group of people who traditionally have not had the services they should.

But there was more to Mr. Wyatt taking the position. In fact, it was not until he stood up to speak at the Nashville roll-out session that it all came together in his mind, and he was able to verbalize what this position with the CJI meant to him. Had Mr. Wyatt not been given the opportunity to go back to work and do tasks and duties on his own, he might not have worked so hard to recover from the effects of a 1991 car accident. Through work, he was able to improve, and prove wrong the daunting prognosis of his physicians.

According to Mr. Wyatt, the first job he had after his car accident gave him, “FREEDOM!” Mr. Wyatt understands that work played a role in his recovery and ultimately in who he is today. Through his work experience, he gained friendships, knowledge and skills, and learned to take chances. Just as Mr. Wyatt realized he had the chance to do more than he ever thought he could, he wants people with mental illness and co-occurring disorders, through the CJI initiative, to have the opportunity to do more, through work, than they ever believed they could. In conclusion, Mr. Wyatt said, “disability should not matter. You should be judged on the fact that you want to work and whether you can do the job.”

Alicia A. Cone, is project research and development coordinator with the Council on Developmental Disabilities.

continued from page 6

• **NOTE 5** | The picture wall grew during our two-day training to include photos of each and every participant. Serving as a frame for the flip chart showing the group members’ votes on what they had chosen to be their top issues (getting a job was number one, increasing their pension amounts last), they became a major source of interest and small talk. Finally, one of the participants caught on to us and we gave each person their picture as they walked out the door.

• **NOTE 6** | When we used our individual and family support model as an example of what we felt would be the most cost effective way for the Ministry to expand supports and services, one of the Shtimë directors scratched his head and said he wasn’t sure it would be feasible. As we probed deeper, we found he wanted to know how we would address the “food distribution” problem this would create. Probing even further, we realized that he could not conceive that folks would just go to their local markets like everyone else.

• **NOTE 7** | The translators, Adnan and Lodenoh, were ready for a break after being our constant companions. We had spent two long days with the self-advocacy groups. Everyone there was in agreement that people with disabilities in Kosovo need to work on getting more power. It wasn’t until we were winding down that we realized that when we talked about power, we meant collective advocacy. When our group members had talked about power, they were talking about electricity! (Power availability in Kosovo is very erratic. Generators abound as scheduled and unscheduled power outages occur on a daily basis.)

Seven days and nights later we thanked our hosts and translators and packed for the trip home. Then we got to the airport to find our flight—the only one of four flights out for the entire country—for that day was cancelled. With an unexpected opening for leisure, we decided to take a break and wander around Pristina.

In addition to our touristy postcards, we eventually arrived home with pictures and stories from the people themselves to put into a book to sell here on the groups’ behalf. The coordinators of the groups earn 138 euros per month. As foreign national support begins to lag, it shouldn’t take much fundraising on our part to help them keep going. We can’t wait to go back and see how much power they’ve mustered by putting our training into action.

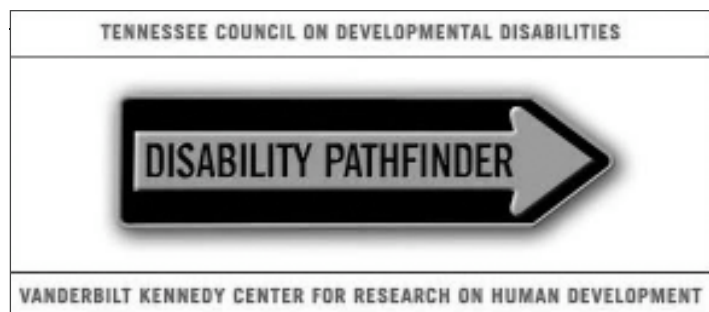
For a copy of the book, *Vetevendosje: Self-determination Kosovo Style*, contact Ruthie-Marie Beckwith at empfanatic@aol.com

Ruthie-Marie Beckwith is executive director of the Tennessee Microboard Association.

Mark Friedman is executive director of the Middle Tennessee Advocacy Center.

NEWS FROM PATHFINDER

By Melissa Fortson



Tennessee Disability Pathfinder has phone, Web, and print resources in English and Spanish to connect the Tennessee disability community with service providers. Referral services, free of cost, are provided to persons with disabilities, family members, service providers, and advocates. Pathfinder is a joint project of the Tennessee Council on Developmental Disabilities and the Vanderbilt Kennedy Center for Research on Human Development.

ACCESS NASHVILLE PROJECT HONORED

Access Nashville, a volunteer project providing information about the accessibility of restaurants, hotels, and attractions in downtown Nashville, recently was honored at the 20th Anniversary Mary Catherine Strobel Awards Luncheon. The awards, a program of Hands On Nashville, honor those who have "given their time and talents to improve the lives of others in Middle Tennessee." A finalist in the Volunteer Innovator category, the Access Nashville Steering Committee was recognized for its creative response to unmet community needs. This volunteer project was initiated by Pathfinder director Carole Moore-Slater, who serves as the Steering Committee chair. Pathfinder disability resource specialist Melissa Fortson is also a committee member. For more information on how to become involved with Access Nashville or replicate this grass-roots project in your community, visit the Access Nashville Web site at www.accessnashvilleonline.org.

RESOURCE SPOTLIGHT: LEGAL SELF-HELP BOOKLETS

The Legal Aid Society of Middle Tennessee and the Cumberland provides free, easy to read legal help booklets. The booklets, which advise persons of their legal rights and legal problems they can solve themselves, are available on the Legal Aid Society's Web site at <http://www.las.org/> or by calling 1-800-238-1443. Topics include Health Care (Advance Care Plan/Living Will, Medicare, TennCare), Housing (Renter's Rights and Low-Cost Housing), and an Advocate's Page. Self-help booklets and telephone assistance is also available en Español.

PATHFINDER DISABILITY CALENDAR

Pathfinder maintains the Pathfinder Disability Calendar, an Internet calendar of trainings, conferences, meetings, and other disability-related events. Organizations post events to this interactive calendar, the most comprehensive listing of Tennessee disability events. To access the calendar, go to the Pathfinder Web site at <http://www.familypathfinder.org> and click on "Pathfinder Disability Calendar." For more information, or to request an access code that will allow your organization to post events, contact Pathfinder.

STAY CONNECTED WITH PATHFINDER

Pathfinder publishes *The Pathfinder*, an e-newsletter containing information about program activities and other disability-related resources in Tennessee. Past issues of the publication are archived on the Pathfinder Web site (under Pathfinder Features, click on "The Pathfinder: News from Tennessee Disability Pathfinder." To receive future news from Tennessee Disability Pathfinder via e-mail, please contact us at tnpathfinder@vanderbilt.edu.

FOR FURTHER INFORMATION:

Tennessee Disability Pathfinder
(615) 322-8529 (Nashville area)
(800) 640-4636 (toll-free, English & Español)
(800) 273-9595 (TTY)
www.familypathfinder.org
tnpathfinder@vanderbilt.edu

2004-2005 DIRECTORY DISCOUNT: NOW ONLY \$10

2004-2005 Tennessee Disability Services & Supports Directory, published by the Tennessee Disability Pathfinder Office, is a source of information regarding state and local programs and services. The newest edi-

tion is available by geographic region (East, Middle, and West Tennessee). Order forms are available online at <http://kc.vanderbilt.edu/devents/order.html>



TENNESSEE SPOTLIGHT

BREKA S. MOORE, YLF 2001 Student Delegate, recently graduated from Dyersburg State Community College with an Associate Degree in Early Childhood Education. While attending Dyersburg State, she was selected as Homecoming Queen, was a member of the Student Government Association, a member of Phi Theta Kappa Honor Society, and served as Student Ambassador. Ms. Moore also was nominated for Who's Who Among Students in American Junior Colleges and the National Dean's List.

Partners grad **HEATHER WILSON** (02-03) made front page news, in the Knoxville area *Saturday News Sentinel*. The 2-pager, complete with color photos of Ms. Wilson and her family (human and canine), was entitled Disability No Distraction. In the article, Ms. Wilson discusses her experiences with school, employment, accessibility in her home and community, and her desire for people to use People First Language when speaking about persons with disabilities.

YLF 2005 Student Delegate **EDWARD MITCHELL** not only had a great article written about him in the *Jackson Sun*, he also had an Edward Mitchell Day officially named after him by the Jackson city government, in honor of his courage and perseverance. In March 2003, Mr. Mitchell was hit by a car while riding his bicycle, and the driver fled the scene. After two surgeries, Mr. Mitchell was left paralyzed from the waist down. He is currently attending Lane College, which is affiliated with the Christian Methodist Episcopal Church.

DRAKE AND TAYLOR REECE, the sons of Partners grad Christy Wells-Reece (00-01) were recently mentioned in the *Bradley News Weekly* for their community service walk. Their dad, Tracy, was diagnosed with

Multiple Sclerosis (MS) three years ago, and the boys have been actively involved with the Cleveland MS Walk by participating as walkers, helping at rest stations and raising money by selling candy and MS Hope bracelets. Their mom, Christy, is the Cleveland MS Self Help Group leader.

Although self-advocate, community leader and honorary Partners graduate, **LORI SIEGAL** passed away this past November of heart difficulties, her spirit lives on. In April, Ms. Siegal was honored as the winner of the Volunteer Memphis Spirit of Giving Board Member of the Year, for her service to the Down Syndrome Association of the Mid-South. Her inspiring story was also featured in "The Circle Unbroken", a collection of stories released by the Womens Foundation for Greater Memphis.

LIZZY SOLOMON, daughter of Council staff Ned Andrew Solomon and Easter Seals Child Development Center director, Amy Harris-Solomon, was recently named a finalist in the Guardian Life Insurance Company of America 2006 Girls Going Places Scholarship Program, a national competition that recognizes and rewards teenaged girls who demonstrate exceptional entrepreneurship and community service. Fifteen winners were selected from more than 5,000 nominations from across the nation. Guardian has awarded the fifteen girls a total of \$30,000 to be used toward their college education or their businesses. The first, second and third place winners received prizes of \$10,000, \$5,000 and \$3,000, respectively, and 12 finalists were granted prizes of \$1,000 each. Ms. Solomon, 12, was honored as founder and owner of Lizzy's Lines, a greeting card company that features note cards for children with disabilities.

CONTINUED FROM PAGE 3

The tapes also described how masks and statues gradually were made from materials like plastic, which became available as the people were exposed to western civilization and their traditions slowly changed. Listening to these descriptions, I learned about customs and people I had never heard of before. To me, the information on tape was just as interesting as the materials I could feel and added a lot to the experience.

We spent a long time walking that day, and since my friend and I have some problems with arthritis, it was frustrating that there were no benches or areas where we could sit

down and relax for a few minutes. I hope that the museum will put in a few benches or chairs so that seniors and those who have some trouble walking will be more comfortable.

I really enjoyed my visit to this exhibit and hope the Frist continues to make art more accessible to those of us who are visually impaired. I have been told they are working on making an Egyptian exhibit accessible and I look forward to seeing it. I want to encourage blind and visually impaired persons to visit accessible museums in the future. It's a great opportunity to learn about the past,

examine beautiful things and enjoy art through touch.

- Carol Francisco

Susie Elder, educator for outreach, walked with me through the grand halls and galleries of the Frist, explaining the interior. My remembrance of the building is of the former downtown post office. There has been a great transition plus a respect for the history of the building. It is on the Historical Registry.

When Ms. Elder and I arrived at the Educational Gallery, Braille signs were on the entrance walls. The room was large enough

CONTINUED ON PAGE 15

MEET THE 2006 YOUTH LEADERSHIP FORUM STUDENT DELEGATES

By Ned Andrew Solomon

It might be a smaller group of delegates than usual, but YLF always has been—and always should be—about quality, not quantity. These future leaders have the quality part down. They are actors, singers, athletes, student council officers, church group leaders, debaters, advocates, community volunteers, tutors, equestrians, sports team managers, Scouts, journalists and techno wizards. Even though they hail from different towns and cities across the State, they possess a common desire to meet on Vanderbilt campus June 5-8, to learn more and teach others about the disabilities that have become a challenging but character-building aspect of their lives.

Please join the Council on Developmental Disabilities in welcoming the following accepted students, as you read excerpts from their application essays.

"I don't want to stay in high school until I'm 22. I want to go on a trip, and to the prom, and then on to college. After I graduate and go to the prom, I want to get married and get a job." — **Lauren Butler, Knoxville**



"As for the future, I want to continue with Company D (Dancers), and bring joy and positive awareness to the public. After high school, I plan to attend cosmetology school and work in a salon as a stylist. I feel the more settings that I can be involved in, the more people will understand that I am a capable individual and a positive contributor to society. I believe that actions speak louder than words." —



Amanda Cash, Cordova

"I have helped make changes in my community. I have done things such as have Braille signs put up in public buildings such as restaurants. I have gotten restaurants to supply Braille menus. I have gotten Braille signs put up in schools I have attended...I also help advocate for myself and other high school students. I help with the local Arc, and recently became a member of a State committee...I would like to be part of YLF so I can expand my network of fellow advocates in my State." — **Kaitlyn Cherry, Fayetteville**



"My mom has influenced me. She has always been in my life and she helps me. She gives me jobs to do around the house and teaches me how to do things. She helped me achieve some goals like my homework, passing the gateway tests and graduating from high school. She tells me that I can do it." — **Lyndsey Gill, Bartlett**

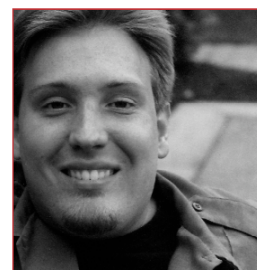
"I have worked very hard to accomplish my dreams and goals, in spite of my disability. I am graduating from high school this year with a B average, and I have been accepted to attend MTSU in the fall. My family has always encouraged me to be and do whatever was important to me...I learned from a young age how important it was to be a self-advocate, and I've had lots of support and guidance from teachers, family and friends...I've never used my disability as a crutch, but instead have focused on creative ways to get things done." — **Johnsie Hays, Maryville**



"School itself is an experience...luckily, I have never been teased. Most kids are actually curious and like seeing the tools, magnifiers and other aids I use. I do have to work harder and longer than most students to keep up with the work, but these challenges have helped in my determination and perseverance. Being a part of public schools has helped me learn to

speak up for myself when I need help or when I am having trouble." — **Rachel Hockenberger, Kingston Springs**

"In our family, we have life stories that my mom reminds me of from time to time. There was a time when I was younger and grocery shopping at the Bi-Lo grocery store in Franklin. The store had just gotten new check-out stations with the scanners. After the boxes and cans were scanned, I tried to scan myself. It didn't work. My mom told me that it wouldn't work because I was priceless. Sometimes I feel different because of my birth defect, but I remember I am priceless." —



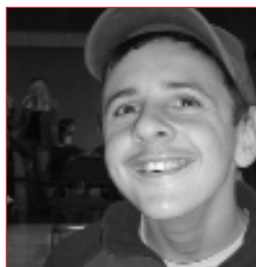
James "Preston" Hess, Franklin



"My 9th grade religion teacher was only my instructor for six months but her words changed my life. She influenced me by challenging me to go the extra mile to learn... She made learning about the Bible fun and interesting. If I or anyone else had a question about the lesson, she would give an example and then say,

'Think about it.' She really helped me to think more for myself."—**Jessica Horner, Memphis**

"In 2nd grade, I realized I would be using a wheelchair not a walker like in first grade. I felt different. I didn't want to be different. It's hard being different sometimes...My kindergarten teacher, Carrie Padgett, was a special teacher. She taught me that because I may be in a chair that I didn't have to depend on others. I watched her control a group of rowdy kids without losing her patience or using unkind words. Wheelchairs aren't the end of things. She was crowned Ms. Wheelchair TN and showed her talents and beauty despite her disability. People can reach their goals even with obstacles."— **John Matejko, Madison**

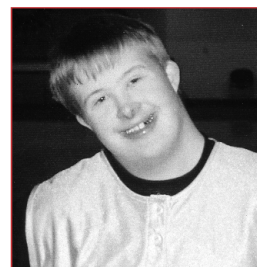


"In the 5th grade, a kid mocked a seizure which I had when I was younger. Everyone laughed. I felt like they were laughing at me. It hurt my feelings. I learned to not treat others that way or to make



fun of other people with disabilities. This Forum would help me teach others about people with disabilities so they know better than to make fun."— **Sarah Mathis, Manchester**

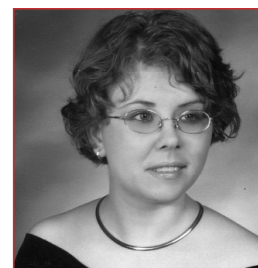
"Being a person with a disability isn't always easy. Some of these experiences I don't really like to talk about. One happened last year at school. Mr. Broekman, the head of our school, used the word 'retarded' during a school assembly. The minute he said that word, he knew he had made a mistake. All of my friends were really supportive, because they know how much I dislike that word. At the next assembly, Mr. Broekman apologized to me and my classmates. He was really nice to do that." — **Will McMillan, Nashville**



"I am uniquely qualified to be a delegate to the Tennessee Youth Leadership Forum because I would like to learn more about my own disabilities. I would like to learn more about where I can go for assistance for my disabilities. Also, I can teach others what I know. I would like to know about other people's disabilities, which I can take to college with me and throughout life."— **Kristin Pettway, Hixson**



"There was one thing that I had not prepared myself for, nor was I expecting, and it happened almost instantly. The majority of my friends deserted me in the blink of an eye once they found out I was going deaf—whether it was frustration from speaking to me, or the fact that they just didn't care. This was extremely hard to deal with, but over time I have come to notice that the friends I have now are the best that I could ever ask for, and that is because they came to me after I went deaf and accepted me for who I am." — **Stephanie West, Oak Ridge**



For more information about the Tennessee Youth Leadership Forum, please contact YLF director Ned Andrew Solomon at 615-532-6556, or by e-mail at ned.solomon@state.tn.us.



ARLINGTON DEVELOPMENTAL CENTER: THE CLOSING IS IN SIGHT

By Steven Sheegog

One Spring day in late April, my wife and I were driving around in the Arlington area, which is located in northeast Shelby County, investigating the housing market. Near the new Arlington High School, I noticed a sign which provided directions to the Arlington Developmental Center. Although through my participation in the Tennessee Council on Development Disabilities' "Partners in Policymaking" program I was familiar with the history of the Arlington Developmental Center, I had never seen it. So I decided to drive over to take a look.

We when we approached the Center, I expected to see a more traditional hospital—not the large campus of small buildings and well-maintained grounds. But I realized for many of its clients and their families, the Center was not a beautiful place. The University of Tennessee Health Science Center College of Nursing Web page describes Arlington Developmental Center as a state funded residential facility in which "its staff provides services to people with severe to profound mental retardation and chronic developmental challenges."

Many families—in order to receive needed services and medical attention—may feel that they have no choice but to place their family member in an institutional setting. This always has been disturbing to me, because I remember the news reports concerning poor care and abuse at the Center. All of this may change since People First of Tennessee won its battle to use the federal courts to close Arlington.

According to an Internet article in *Mouth* magazine, issue #43, dated July 1997, every DD institution in the State will shut down in the next five years. Well nine years have passed and it looks like Arlington will finally close. The Tennessee Division of Mental Retardation Services deputy commissioner, Stephen H. Norris, hired Kathleen "Cate" Newbanks to

become the West Tennessee Regional Director and she is managing the closing of Arlington.



CATE NEWBANKS

The March 2006 issue of *Personally Speaking* describes Ms. Newbanks as the new DMRS Sheriff in the West Region. It further states that Ms. Newbanks is a doer who gets things accomplished. Others who have met and worked with Ms. Newbanks speak highly of her.

Ms. Newbanks' new position here in Tennessee must be a breath of fresh air from her prior position as deputy secretary for Community-based Care and Family Self-Sufficiency in Florida's Department of Children and Families. According to a *St. Petersburg Times* Online article dated July 30, 2004, the department's head, Jerry Regier, was under heavy criticism. Ms. Newbanks resigned along with two other top aides in the department.

Although Ms. Newbanks is extremely busy managing the West Region office and the Arlington closing, she agreed to answer a few questions regarding the project:

BG: What is the timeline for closing Arlington Developmental Center?

CN: Official closure will be accomplished prior to June 30, 2008.

BG: How many small ICFs/MR will be built?

CN: Twelve are planned, but an additional four could be added, if the need dictates.

BG: Where will the new 4-bed ICFs/MR be located?

CN: Planned for the Arlington area (preferably on the old Arlington campus).

BG: Who will own the new ICFs/MR, and who will provide the support services to people who live in them? (State owned, State employees?)

CN: The State will own and operate.

BG: What is the difference between a 4-bed ICF/MR, and a 4-bed wavier program?

CG: I'm not clear what is meant by a 4-bed waiver program. The difference between the residential waiver program and the 4-bed ICF/MR program is the physical plan requirements (ICFs/MR have stricter standards), the provision of services (ICF/MR builds many of the required services into the rate, and the waiver allows for more choice of service provider), and the funding source (ICF/MR funded by TennCare and waiver funded by DMRS).

In retrospect, Arlington is evolving rather than closing. This may be a more suitable outcome for those who opposed the closing of Arlington, such as its Parent Guardian Association. I really don't know. The only thing I know is that change may be difficult and slow, but it is coming.

NOTE: Cate Newbanks hosted the first annual West Tennessee Regional Springboard Conference. The three-day forum, May 21 – 23, was held at the University Center on the University of Memphis campus. At the event, families and the workforce had the opportunity to discover the resources available from the West Tennessee regional network. The Springboard Conference was co-sponsored with the University of Memphis and Community Services Network.

Steven Sheegog represents the Memphis-Delta Development District on the Tennessee Council on Developmental Disabilities.

UPCOMING ARTS ISSUE 2006

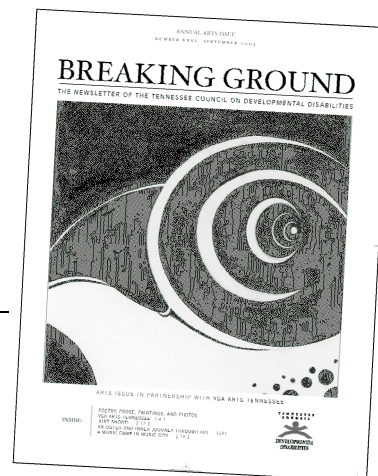
The editorial staff of *Breaking Ground* invite you to contribute to a special issue devoted to the arts coming in September 2006. All entries must be submitted by July 15.

Do you write short stories or poetry? Do you paint, draw, or take pictures? Then we'd like to see your work for possible publication! The editor will consider:

- fiction up to 1,000 words and poems
- photographs, and all other forms of artwork

Our color pages are limited, so the submitted material must reproduce well in black-and-white. Content is devoted to materials by or about people with disabilities.

We'll give contributors a prominent by-line, a biographical note, and copies of the issue. Please include your name, hometown, and a two or three sentence biography with your submission.



PLEASE ADDRESS YOUR SUBMISSIONS TO:

Breaking Ground Arts Issue,
c/o Ned Andrew Solomon,
Tennessee Council on
Developmental Disabilities
Andrew Jackson Building
500 Deaderick Street,
13th Floor Suite 1310,
Nashville, TN 37243
E-mail: ned.solomon@state.tn.us
Phone: 615-532-6556
FAX: 615-532-6964

CONTINUED FROM PAGE 11

to hold a U-Shape area with eleven pieces of African art, all available to touch. In front of each art piece, there was a Braille explanation attached. The art objects stood on a foundation with different texture, in order for the non-visual person to locate the object for examination.

The art objects ranged from statues, hand-made cloth, woven grasses and beads for jewelry. The objects were lent to the Frist for the purpose of the Touch exhibit. All the art objects, which were made in the nineteenth and early twentieth centuries, were models of ancient African objects that had a certain purpose in their respective villages.

Ms. Elder and I decided to take a different approach in examining the art objects. I would feel the object, then Ms. Elder and I discussed what we had each observed from our two separate perspectives. Sometimes shapes, carvings and textures

were different from each of our examinations. We thoroughly enjoyed learning from each other. After our comparisons, I read the Braille inscriptions.

My walk at the Frist will be a highlight of 2006. It was a treasure I found, and a pleasure I will not forget.

- Sally Ann Gentry

Carol Francisco is a graduate of the 2005-06 Partners in Policymaking™ Leadership Institute and is president of the Middle Tennessee Council for the Blind.

Sally Ann Gentry retired from the Department of Human Services after 23 years. She is active in the disability community, and is a member of the VSA Board of Tennessee.

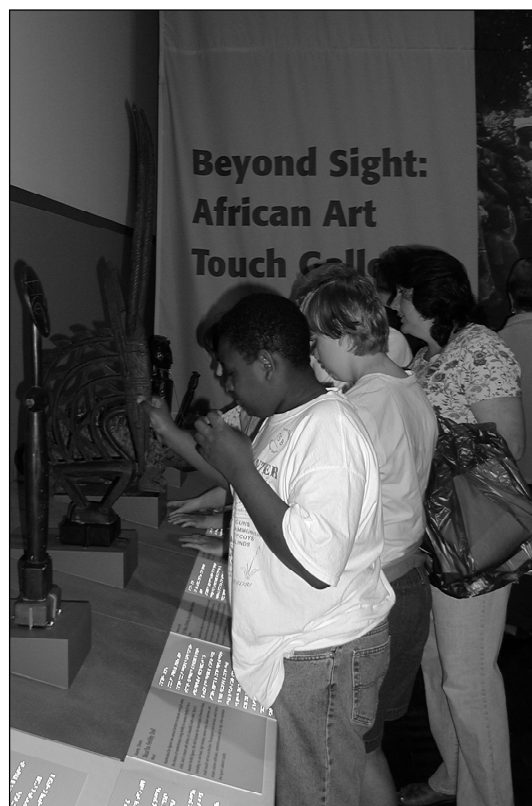


PHOTO PROVIDED BY FRIST CENTER FOR THE VISUAL ARTS

MARTIN MCGRATH: LEADING BY EXAMPLE

By Deana Claiborne

April 18, 2006, was one of those brilliant Spring days that reminds you that Summer is not far away. The weather was unusually warm as hundreds of Middle Tennessee volunteers, representatives from business, faith-based organizations, and area charities gathered to honor 130 individuals nominated for the 2006 Mary Catherine Strobel Awards. Among those nominees making their way into the large conference area was Martin McGrath, an unassuming man whose volunteer work with United Cerebral Palsy of Middle Tennessee has spanned more than two decades. U.S. Representative Jim Cooper welcomed everyone to the event, which he called, "The Academy Awards for Volunteers."

As I searched for Martin in the growing crowd, my memory flashed back to an incident over eight years ago: United Cerebral Palsy's annual family picnic. All of our staff, volunteers, and families had enjoyed a pleasant afternoon in Centennial Park. When the event wore down, and people began to depart, we awaited the AccessRide vehicle that was scheduled to take Martin home. Several vans came and departed with other riders, but none would take Martin because "he is not on the manifest for this vehicle." We were assured that Martin's ride was "in route."

The minutes passed, and everyone else left. My husband and I stayed with Martin, awaiting the van. After what seemed like an inordinately long time, we called and left messages on the answering service. Still, no transportation for Martin. It grew dark. We called the MTA emergency number. No one answered. Everyone had gone home! That is when we realized: Martin had been left behind.

Left behind . . . This is an apt metaphor for the lives of many children and adults with disabilities in our State, including Martin. While we have quality Medicaid Waiver services for persons with intellectual disabilities, essential supports such as personal attendant care, physical, occupational & speech therapy, assistive technology, and other services that ensure active, fulfilling, self-directed and independent lives are not obtainable by persons with other developmental and acquired disabilities. Martin, like many other persons with significant functional disabilities, is a strong advocate for home and community based long-term services and supports for our State.

In 1978, Martin wrote his first book: *"Give Us the Knife: Carving a Lifestyle."* In his book, Martin chronicles the beginnings of the disability movement and the impact that the then-unique ideas of independent living had on his personal philosophy of life. The book describes



PHOTO BY DEANA CLAIBORNE

his personal victories, as well as the loss he experienced when his mother died in 1964 and his father passed away only nine years later.

On that long-ago Summer night, as we tried to find transportation for Martin and his power wheelchair, Martin was worried, but not in the way you would expect. He was concerned that he had inconvenienced us because we were staying with him. Martin McGrath is the most genuinely selfless person I have ever met. Over the years, he has demonstrated his concern for others through countless acts of kindness, both large and small.

Martin has an amazing ability to educate without being patronizing. He knows how to communicate the philosophy of independent living to people who have difficulty looking beyond a wheelchair. One of Martin's greatest skills is communication, yet his cerebral palsy affects his ability to speak. Martin teaches us every day that the best information we gain about our service population requires quality listening time, and great respect.

Like virtually all people with disabilities, Martin has been the victim of prejudice. His intellect and his great compassion are often overlooked. From a simple trip to the grocery store to a meeting that he is required to facilitate, Martin proves over and over again that giving in to misconceptions about persons with disabilities does great disservice to our entire community.

Martin's work with UCP has resulted in an unprecedented involvement of our service population and their families as volunteers. Last year, he was a leader on the team that mobilized over 2,000 volunteers, providing direct services to more than 3,500 individuals and families with a wide variety of disabilities through programs like wheelchair ramp construction and the durable Medical and Adaptive Equipment Exchange.

In 2005, the UCP Board of Directors accorded Martin McGrath the highest mark of respect in leadership when he was appointed President of the Board of Directors. Martin is the first individual with a major life disability to serve in this role. In taking on this challenge, Martin leads with the simple dignity and integrity that has characterized his lifetime

CONTINUED ON PAGE 19

BILL TO CREATE TASK FORCE TO PLAN FOR DEVELOPMENTAL DISABILITIES SERVICES PASSES STATE LEGISLATURE

By William Edington

The Council on Developmental Disabilities, working with its partners in the Alliance for Disability Policy (the Disability Law & Advocacy Center, The Arc of Tennessee, and UCP of Middle Tennessee) developed state legislation for the 2006 session that would begin to address the needs of Tennesseans with developmental disabilities other than mental retardation.

BACKGROUND

In a major planning effort in 1999-2000, a statewide commission reviewed Tennessee's laws regarding mental health and mental retardation services and subsequently made recommendations to revise those laws. Those recommendations were passed by the General Assembly and the changes became effective in 2001 and 2002. One of the most far-reaching changes was to expand eligibility from mental retardation to encompass persons with all developmental disabilities.

Since the law to expand eligibility to all developmental disabilities became effective in March 2002, no funds have been allocated to provide comprehensive home and community based services to this group of people. Although significant services exist for persons with mental retardation, no such equivalent services exist for persons with autism, cerebral palsy, cystic fibrosis, spina bifida and other conditions that occur in the developmental years. There is no mechanism in place to determine which persons with developmental disabilities need comprehensive home and community based services, and to identify what these individuals need. There is also no intake system for these individuals to access a service delivery system. And, no plan exists to implement any form of comprehensive home and community based services for persons with developmental disabilities other than mental retardation.

LEGISLATION

The Alliance for Disability Policy drafted a bill that would begin to address the needs of persons with developmental disabilities other than mental retardation. The bill was initially introduced as SB 2766 in the State Senate by Senator Jim Tracy and as HB 2844 in the House of Representatives by Representative Charles Curtiss. The bill was ultimately co-sponsored by ten Senators and 26 Representatives. The bill was passed by both the State Senate and the House of Representatives and was signed by the Governor on May 4, 2006. The legislation will become effective on July 1, 2006.

The legislation calls for the Division of Mental Retardation Services to establish a taskforce:

- to conduct a statewide needs assessment of the needs of persons with a developmental disability other than mental retardation for whom comprehensive home and community-based services do not exist,
- to identify the capacity of the system to meet those needs, and
- by June 30, 2007, to develop a plan to provide cost-effective home and community-based services for those persons.

The Taskforce will be established by the Division of Mental Retardation Services and will coordinate with other relevant State agencies including:

- the Department of Mental Health and Developmental Disabilities,



- the Commission on Aging and Disabilities, and
- the Department of Education.

FEDERAL DEFINITION OF DEVELOPMENTAL DISABILITY

Developmental disability means a severe, chronic disability of an individual that -

- (i) is attributable to a mental or physical impairment or combination of mental and physical impairments;
- (ii) is manifested before the individual attains age 22;
- (iii) is likely to continue indefinitely;
- (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity:
 - (I) Self-care,
 - (II) Receptive and expressive language,
 - (III) Learning,
 - (IV) Mobility
 - (V) Self-direction,
 - (VI) Capacity for independent living,
 - (VII) Economic self-sufficiency; and
- (v) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

Infants and Young Children - An individual from birth to age 9, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting 3 or more of the criteria described in clauses (i) through (v) above if the individual, without services and supports, has a high probability of meeting those criteria later in life.

William Edington is legislative and public policy coordinator for the Council on Developmental Disabilities.

PROMOTING A BALANCED LONG-TERM CARE SYSTEM IN TENNESSEE

By Brian McGuire, AARP Tennessee



PHOTO CREDIT: PEYTON HOGE

Three major events over the last three months highlight a critical phase of the Choices for Care Campaign, which is calling on Governor Phil Bredesen to create a more balanced long-term care (LTC) system for Tennesseans who need supports and services. Tennessee is last in the nation in providing options in long-term care. The cost of these in-home and community services is typically one-third to one-half less than the cost of nursing home care.

RALLY PROMOTES CHOICES IN LONG-TERM CARE

On April 5, AARP Tennessee, the Tennessee Disability Coalition, and many other organizations organized a public rally at the State Capitol on the issue of providing choices in long-term care services.

AARP Visiting Scholar and internationally renowned long-term care visionary, Dr. Bill Thomas, joined Governor Bredesen and 1,200 Tennesseans for the rally. Dr. Thomas energized the crowd with his vision for how long-term care could be in Tennessee, and Governor Bredesen publicly committed to expand services to include adult day care, in-home respite care, and other services. The governor was presented with over 17,000 signed post cards, urging him to move the State forward, and give people who need long-term care real choices in where and how they receive these services.

AARP RELEASES LONG-TERM CARE SURVEY OF TENNESSEE VOTERS

A new survey of Tennessee registered voters age 35 and older showed overwhelming support for giving residents choices for long-term care in the home and community. In addition, Tennessee voters say they are more likely to vote for State candidates who support allowing funds now used only for nursing homes to also be available for alternative services which help older and disabled Tennesseans remain independent.

Among the survey's highlights:

- Half of Tennessee voters age 35 and older say they are likely to need long-term care services for themselves or their family members in the next five years. Over half of these voters are worried about being able to receive long-term care services in the setting of their choice.

- Almost all believe it is important to have long-term care services that would enable them or their family members to stay at home as long as possible when care is needed.
- More than three-quarters want to receive long-term care services at home from a nurse or personal care aide when care is needed and their family members or friends cannot provide this care. Very few (5%) would prefer to receive care in a nursing home.
- Almost eight in ten support AARP advocating for funds now used only for nursing homes to also be available for long-term care services that help people stay at home.
- Nearly seven in ten say they would be more likely to vote for a candidate for State Governor or for State Legislature who supports allowing funds now used only for nursing homes to also be available for long-term care services that help people stay at home.

CONSULTANT'S REPORT PROVIDES ROADMAP TO A BALANCED LONG-TERM CARE SYSTEM

A new report by one of the nation's leading long-term care experts offers concrete steps Tennessee can take to give older and disabled citizens choices for care, beyond that provided in nursing homes. The study was presented at a round-table forum of policymakers in the State Capitol on April 24.

Improving Long-Term Care Services in Tennessee: Meeting the Changing Needs of a Growing Population

was prepared by Roger Auerbach, who directed Oregon's model long-term care system for five years. Auerbach is also a senior consultant to The Lewin Group, and specializes in the development and implementation of innovative systems to minimize institutional care. Here is a summary of some of the key findings under each of these areas:

ACCESS is critical to individuals who need information on LTC services. Tennessee should continue the development of a single entry point system through the Tennessee Commission on Aging and Disability and the area agencies so that people can access information about LTC services, receive counseling about options and service availability, assess need, and determine eligibility for public programs.

FINANCING must be available to support individual choice of where and how Tennesseans receive LTC services. Tennessee should develop a plan for a unified or "global" budget that is flexible enough to allow an eligible

individual to choose where to receive LTC services and supports.

SERVICES and supports must be available across settings, and the State must attract enough providers of these services. Tennessee should include assisted living, in-home respite care and adult day care services in the current home and community based services waiver; adopt a variety of methods to encourage and sustain family caregiving; and provide increased reimbursement for providers of home care services.

QUALITY is essential to LTC services, and the State should have sufficient structures in place to monitor the quality of services. Tennessee should continue to develop systems designed to monitor quality and to detect and resolve problems in the LTC system.

While Governor Bredesen has made commitments to include some additional services in the HCBS waiver, as of press time there is still no firm commitment on creating the kind of flexible budgeting that will place Home and Community Based Services on a more level playing field with nursing home care and allow money to follow the person to the services of their choice.

For a copy of the survey or report, or to learn how to get involved in the Choices for Care campaign, please visit www.aarp.org/tn.

Brian McGuire is legislative director for the Tennessee State AARP office

CONTINUED FROM PAGE 16

work with UCP. He has been instrumental in promoting the synergy among families helping each other, by leading the effort as an individual with a disability and in expanding volunteerism throughout our agency, and indeed throughout our community.

Martin advocates for others, yet he rarely asks for anything for himself. Most people do not realize that Martin faces having to live in a nursing home if we don't change the current focus of our State systems and supports.

Recently, Martin and I attended the UCP/ARC National Disability Policy Collaboration Conference in Washington, D.C., which addressed policy issues and national concerns of people with disabilities. After the physically exhausting conference, Martin became ill and was quite sick on the flight home. Even though an inconsiderate and irate passenger voiced negative comments, Martin maintained his ever-present positive attitude and by the end of the week, he was ready to go again. Martin simply doesn't stop.

Flash forward once again to the Mary Catherine Strobel Awards: Martin had been nominated in the category of "Direct Service Volunteer." Individuals eligible for this award have made a long-term commitment to an agency. Their service is considered extraordinary, with emphasis on longevity and focus as well as impact to the agency and its clients. Martin was one of over 70 community volunteers nominated in this category alone.

The names of the top five nominees were called. Martin was one of the top five! He and the other four nominees made their way to the stage. WTVF news anchor Rhoji Johnston described the tremendous work of each of the stellar finalists in this category.

A pause, as over 800 people collectively held their breath awaiting the name of the 2006 Award Recipient . . . and the recipient was . . . Martin McGrath! The room erupted in applause, and then, people in different areas of the great room simultaneously arose from their seats. The entire audience was on its feet, riotously clapping. Martin was receiving a standing ovation!

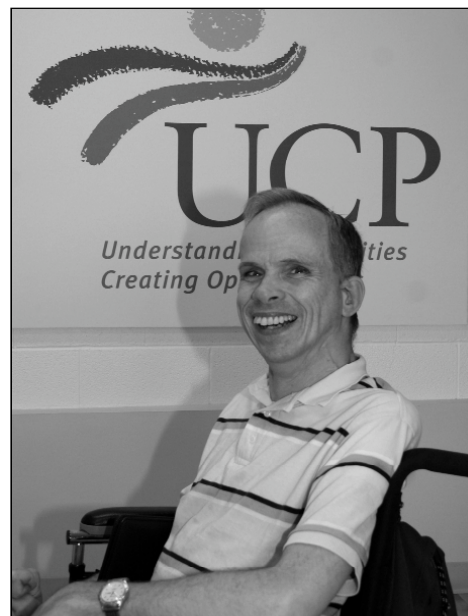


PHOTO BY DEANA CLAIBORNE

The community has recognized what those of us at UCP have known all along: Martin McGrath is a grassroots volunteer in the truest sense of the word. He leads by example, and he inspires through his unfailing moral compass and great personal vision for the population we serve.

Deana Claiborne has been executive director of United Cerebral Palsy of Middle Tennessee since 1993. She is currently State president of the League of Women Voters, and was a founding member of the Tennessee Alliance on Disability Policy, along with representatives of the Council on Developmental Disabilities, The Arc of Tennessee, and the Disability Law and Advocacy Center of Tennessee.



MEMBERSHIP AND STAFF

COUNCIL CHAIRPERSONS

Andrea L. Cooper, Chair
Joyce Sievers, Vice Chair

COUNCIL MEMBERS

Michael W. Boyd, Cookeville
Stephanie Brewer Cook, Knoxville
Barron A. Garrett, McMinnville
Mary Dale Greene, Columbia
Nancy Hardin, Dyersburg
Angela Hazlehurst, Jackson
Pamela Huber, Kingsport
Sue Lovlace, Centerville
June Mangum, Memphis
Richard Moore, J.D., Brentwood
Alan Muir, Knoxville
Randy Oliver, Jackson
John D. Piver, Gray
Debbie Riffle, Humboldt
Steven Sheegog, Memphis

Rebecca Smith, McMinnville
Van Veller, Signal Mountain
Marsha Wilson, Antioch

STATE AGENCY REPRESENTATIVES

Philip Wagster
Department of Human Services,
Division of Rehabilitation Services
Joseph E. Fisher
Department of Education,
Division of Special Education
Stephen H. Norris
Department of Finance and Administration,
Division of Mental Retardation Services
Ted R. Fellman
Tennessee Housing Development Agency
Virginia Trotter Betts
Department of Mental Health and
Developmental Disabilities
Richard Kennedy
Commission on Children and Youth

Nancy C. Peace
Commission on Aging and Disability
Theadora Pinnock
Department of Health,
Maternal and Child Health

UNIVERSITY CENTER FOR EXCELLENCE REPRESENTATIVES

Frederick Palmer
UT Center for Health Services
Elisabeth Dykens
Vanderbilt Kennedy Center for
Research on Human Development

PROTECTION & ADVOCACY

Shirley Shea
Disability Law & Advocacy Center
of Tennessee

COUNCIL STAFF

Wanda Willis, Executive Director
Errol Elshtain, Planning Coordinator
Mildred Sparkman, Administrative Secretary
Alicia A. Cone, Coordinator, Project Research
and Development
Lynette Swinford, Fiscal Manager
Ned Solomon, Director, Partners in
Policymaking™ Leadership Institute
William Edington, Legislative and Public
Policy Coordinator
JoEllen Fowler, Administrative Assistant

FOR MORE INFORMATION ABOUT THE COUNCIL, CONTACT THE COUNCIL OFFICE AT The Andrew Jackson Building, 500 Deaderick Street, 13th floor, Suite 1310, Nashville, TN 37243-0228, **TELEPHONE:** 615-532-6615, **TTY:** 615-741-4562, **FAX:** 615-532-6964, **E-MAIL:** tnddc@state.tn.us, **WEB:** www.state.tn.us/cdd

VANDERBILT UNIVERSITY

Vanderbilt Kennedy Center
Peabody Box 40
230 Appleton Place
Nashville, TN 37203

Return Service Requested

Nonprofit Org.
U.S. Postage
PAID
Nashville, TN
Permit No. 85